Experience of living with cancer and comorbid illness

Citation for published version:

Digital Object Identifier (DOI):
10.1136/bmjopen-2016-013383

Link:
Link to publication record in Edinburgh Research Explorer

Document Version:
Publisher's PDF, also known as Version of record

Published In:
BMJ Open

Publisher Rights Statement:
© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2017. All rights reserved. No commercial use is permitted unless otherwise expressly granted. This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/

General rights
Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy
The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.
Experience of living with cancer and comorbid illness: protocol for a qualitative systematic review

Debbie Cavers,1 Sarah Cunningham-Burley,1 Eila Watson,2 Elspeth Banks,3 Christine Campbell1

ABSTRACT

Introduction There are an increasing number of people living with and beyond cancer, whose experience is further complicated by additional long-term health conditions in the context of an ageing population. The supportive care needs of this growing patient group should be recognised and addressed. There is a need to explore the experience of living with cancer and comorbid illness in order to develop optimal models of patient-centred care. This protocol describes a systematic review that aims to identify the qualitative evidence relating to the experience of cancer and comorbid illness for patients, informal carers and professionals, and to highlight areas where more research is needed.

Methods and analysis A systematic review following PRISMA guidance will be undertaken. Medline, Embase, CINAHL, PsycINFO, ASSIA, Sociological Abstracts, Web of Science, SCOPUS, OpenGrey and ProQuest Dissertations and Theses Global databases will be systematically searched for articles relevant to patient, carer and professional experiences. Two independent reviewers will screen articles for inclusion and evaluate them according to the Critical Appraisal Skills Programme tool. Extracted data will be combined using recognised methods of qualitative synthesis to offer new insights into the topic area and for a patient-centred model of care.

Ethics and dissemination The review does not require formal ethical review as no direct patient contact or patient identifiable data is used. Conduct of the review has been approved internally by the University of Edinburgh Centre for Population Health Sciences Ethics Review Committee. Results of the review will be published in a generalist peer-reviewed journal and presented at a relevant conference in addition to informing subsequent empirical work by the authors on this topic area.

INTRODUCTION

Due to the ageing population and better screening, diagnosis and treatments, there are an increasing number of people living with and beyond cancer.¹ The lived experience of these individuals is often complicated by other comorbid chronic illnesses; as many as 78% of people with cancer are living with at least one other condition, the prevalence of which also increases with age.² ³ Therefore, the support needs of people living with multiple complex conditions are enduring and need to be identified and addressed.⁴ In addition to the challenges facing secondary care,⁵ there is increasing recognition of the role of primary care in the provision of ongoing support to patients with cancer, particularly after the completion of hospital-based treatment as patients adjust to life post-treatment, living with ongoing medical issues related to their cancer treatment.⁶ ⁷ This picture becomes more complex in the presence of other long-term conditions, with implications for the coordination of quality care and support.⁸ ⁹

Meeting the needs of people living beyond cancer has been identified as a policy priority,¹⁰ which informed the development of the National Cancer Survivorship Initiative¹¹ in England and Wales; survivorship also forms part of the remit for Scotland’s Better Cancer Care.¹² In many cases, survivorship initiatives and research target the clinical needs related to long-term side effects.¹² However, psychosocial support for survivors of cancer is another important consideration and has implications for the role of primary, secondary and community care. While valuable research has been conducted to

Strengths and limitations of this study

► Protocol for a systematic review of current literature exploring a highly important topic presenting a current challenge to healthcare provision
► Using robust methodology following standardised guidelines
► Scope to inform policy and practice and improve patient care
► Systematic review of qualitative empirical evidence only; does not cover quantitative studies or existing systematic reviews but can give important insights
► Large evidence base for experience of cancer and experience of multimorbidity, but little linking the two bodies of evidence, presenting a challenge to the reviewers

Received 12 July 2016
Revised 7 December 2016
Accepted 16 December 2016
The review aims to move beyond the aggregation of available data to provide further interpretive insights into living with complex illness and define where future research can add to what is known.24

No NHS ethical approval is required for this study as it will not include patient identifiable data. It has been internally approved by the University of Edinburgh Centre for Population Health Sciences Ethics Review Committee (Ref: 8/03/2016).

Eligibility criteria
The review will include qualitative empirical studies, including unpublished grey literature. Qualitative data from mixed methods studies will be screened for inclusion and included if the qualitative component is relevant. Included articles will be published between 2000 and the present day to ensure the currency of the work while enabling a broad view of developing issues to be identified. Articles will be included that address the lived experience of the cancer journey with attention to existing long-term health conditions (developed before or after the cancer diagnosis) and will identify issues related to psychosocial and supportive care as outlined in relation to the anticipated dimensions of interest. Articles will be included from across the cancer continuum from diagnosis through to end of life and will include the perspectives of adult patients (aged ≥18 years), informal carers and healthcare professionals. The review will include only articles published in English.

Studies will be included for any cancer type in combination with one or more comorbid long-term condition (LTC), also described as cancer multimorbidity. Long-term conditions to be included will be guided by those listed in Barnett et al’s paper mapping the epidemiology of multimorbidity3 (see online supplementary appendix 1 for a full list of conditions). The applied definition of long-term conditions is based on ISD Scotland’s report on important long-term conditions in Scotland; the report uses, among others, the Long-Term Conditions Collaborative to define an LTC as, ‘one that requires ongoing care, limits what one can do and is likely to last longer than a year’.25 Long-term side effects of cancer treatment and second primary cancers are not included; experience of second primary cancers is being addressed separately within the research centre. Where it is not possible to determine whether the condition is caused by cancer treatment, the article will be included in the review but analysed separately.
Dimensions of interest
The review focuses on an exploration of the dimensions of lived experience: physical, social, emotional and psychological. From a similar study exploring multiple dimensions of experience, these are expected to include such topics as quality of life, well-being, psychosocial supportive care needs, attitude and identity, perceived continuity and quality of care and influence of personal demographics (age, gender, ethnicity, socioeconomic status). In relation to how services can best meet patients’ needs, topics may include issues of accessing appropriate services, coordination of care for multiple conditions and self-management across the cancer care continuum. The search strategy has been developed to reflect these broad and exploratory domains. The outcomes will depend on the evidence available, and gaps in the evidence will be highlighted for future study.

Information sources
A variety of search strategies will be used to identify potential literature for the review, particularly given the challenges in identifying qualitative evidence. This will primarily involve a literature database search (including grey literature), but will also include citation and snowball searching, known expert consultation via email, related articles searches in PubMed and use of Google scholar. The databases to be consulted are: Medline, Embase, CINAHL, PsycINFO, ASSIA, Sociological Abstracts, Web of Science, SCOPUS and, for grey literature, OpenGrey and ProQuest Dissertations and Theses Global. These are considered sufficient to comprehensively cover the range of topics and disciplines implicated in this review.

Search strategy
The searching phase aims to identify relevant studies for inclusion in the review. The process of searching will begin with individually searching each of the listed databases using an adapted list of search terms; the developed search strategy for Medline is shown in box 1. The search terms will be adapted to suit each database to derive the most meaningful search and will use free text, MeSH and subject headings for maximum sensitivity and specificity.

DATA COLLECTION AND ANALYSIS
Study records
Identified records will be imported into and managed in EndNoteX7. Screened and selected articles will be managed in subsequent EndNote databases in order to track and record the number of records retained at each step. It is anticipated that, given the relative lack of attention in the literature specifically examining the experience of long-term conditions as a cancer survivor, the review will produce a small number of relevant but heterogeneous studies.

Screening
Screening of articles will adhere to the specified inclusion criteria (as detailed earlier; also see box 2).

A three-step screening process will be undertaken to achieve the final set of included articles. First, all titles will be read and those of no obvious relevance will be excluded. This process will be undertaken by the primary reviewer DC. Second, abstract screening will be undertaken by DC and another reviewer to look in more detail for relevance and fit with the inclusion criteria. Any differences in judgement will be resolved by a third reviewer. Finally, full-text articles of remaining studies will be obtained and read, again by DC and one other reviewer, to assess their suitability for inclusion in the final review. Full-text articles deemed to meet the inclusion criteria will be selected and subject to quality appraisal and data extraction.

Data extraction
Data extraction will be managed in Microsoft Excel using a purpose designed proforma. Extracted material will reflect the inclusion criteria and the designated aims of the review, derived from the article as a whole. Information will be gathered on: author; year of publication; country of study; study type; setting; relevant background and impetus for the study; methodological approach and specified methods; patient characteristics and demographics including cancer and comorbidity type; main findings including pertinent themes relating to experience of illness, psychosocial needs and supportive care; strengths and limitations and key relevant discussion points. Extraction of data will be carried out by DC and the second reviewer.

Quality assessment
All included articles will be subject to critical appraisal using the Critical Appraisal Skills Programme (CASP) tool. The 10-item CASP tool was considered to be the most suitable tool to consider the quality parameters of qualitative work and is a well-validated and accepted tool. In reference to the debate on exclusion of qualitative articles on the basis of quality, no articles will be excluded on these grounds alone and a low threshold for inclusion will be applied so that the review can benefit from researcher insight and theoretical as well as empirical contributions. The relative quality of included studies will be critically considered during the analysis and in reference to the developed synthesis. Quality assessment will be undertaken by two independent reviewers, and any differences of opinion will be discussed and reviewed by a third person if no consensus is reached.

Data synthesis
For a qualitative review seeking to explore personal lived experiences, it was important to find a method that acknowledges the different paradigms and positions on which each research output is based as well as allowing for different study methods covering a broad and exploratory topic area. Meta-ethnography, used originally in education research by Noblit and Hare but has more recently been of interest in nursing and health services research, was considered as an appropriate method.
Box 1 Example search strategy for Medline

1. Comorbidity/
2. (Multimorbidity$ or multi-morbidity$ or Co-morbidity$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
3. Chronic Disease/ or (Chronic adj5 Illness$ or conditions$ or disease$).tw.
4. (Long term adj5 (condition$ or illness$ or disease$)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
5. 1 or 2 or 3 or 4
6. Neoplasms$ or Cancer.mp or (Tumour or tumor or Oncology or Neoplasm).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
7. Qualitative Research/ or Qualitative.mp or Interview/ or Interview$.mp or In-depth.mp
8. (Focus Group or Ethnography$ or Observation$ or Participant$ or Respondent$ or View$ or Belief$ or Attitude$ or Awareness or Perspective$ or Understandings$ or Findings or Grounded Theory or Social Construction$ or Theoretical or Phenomenolog$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
9. 7 or 8
10. Psychosocial.mp or Stress, Psychological/ or Social Support/ or Psycho-social.mp or ‘Quality of Life’/ or ‘Experience of Illness’.mp or Experience adj5 Illness or Attitude to Health/ or ‘Quality of Life’.mp or Happ$ or Emotion$.mp or Emotions/
11. Patient satisfaction.mp or Patient Satisfaction/ or ‘Quality of Health Care’/ or ‘Patient Experience’.mp or Satisfaction.mp or ‘Information Preferences’ mp or Decision Making/ or (Decision-making or Decision Making).mp or (Informed choice or Informed Decision Making).mp or Self management.mp or Self Care/ or ‘Continuity of Patient Care’/ or Integrated care.mp
12. Access to Health Care.mp or Health Services Accessibility/
13. Identity.mp or gender.mp or Gender Identity/
14. (Health behaviour or Health behavior).mp.
15. (Help-seeking or Help seeking).mp.
16. (Well-being or Well being).mp or Holistic.mp or Continuity of Care.mp or ‘Continuity of Patient Care’/ or (Fragmented adj5 care).mp or (joined-up or joined up).mp or Integrated care.mp or Diversity of Care.mp
17. Primary care.mp or Primary Health Care/ or Secondary care.mp or Secondary Care/ or Community Care.mp or Community Health Services/ or Ambulatory Care.mp or Ambulatory Care/ or ‘Delivery of Health Care, Integrated’/ or Preventive Health Services/ or Family Practice/ or Shared care.mp or Collaborative care.mp
18. (Patient-centred care or Patient-centred care or Patient-centred or Person-centred or Patient centred or Person centred).mp or Patient-Centered Care/
19. Palliative Care/ or Supportive care.mp or palliative.mp.
20. ‘Health Services Needs and Demand’/ or unmet need.mp or Health Services Research/ or Deprivation$.mp or (Socio-economic or Socioeconomic).mp or Information needs.mp.
21. Survivor$.mp or Survivors/
22. Patient Care Planning/ or Care plan.mp or (Follow-up or Follow up).mp.
23. (‘use of service$’ or ‘service use’ or ‘service adj5 use’).mp.
24. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25. 5 AND 6 AND 9 AND 24

Box 2 Inclusion and exclusion criteria

Inclusion criteria
- Study population—Adults (over 18) with a diagnosis of cancer and at least one other LTC (as specified in online supplementary appendix)
- Articles relating to experience of illness from patient, carer and professional perspectives
- Articles focusing on areas denoted in the dimensions of interest
- Studies with a qualitative empirical design
- Articles published in English

Exclusion criteria
- Articles not meeting the above inclusion criteria
- Articles published before 2000
- Articles focusing on long-term side effects of cancer treatment or second primary cancers alone

for this purpose as it is suited to reviewing a small body of exclusively qualitative evidence and gives rise to a meaningful interpretive account rather than simply aggregating the data. However, thematic synthesis, developed by Thomas and Harden, was also considered as it provides a prescriptive approach that lends itself well to transparency and quality in the conduct and reporting of the review, and in generating hypotheses to meet the review’s objective of generating further empirical research questions. Like meta-ethnography, this method encourages the researcher to consider the concepts and themes that relate different studies—through line by line coding, developing descriptive themes and generating analytic themes—to provide a mutual translation and ultimately produce an interpretive account of the phenomenon of
interest, as a grounded theory approach aims to do with primary data analysis. 37,38

Given the anticipated yield of a small heterogeneous body of evidence meeting the eligibility criteria for the review, a narrative-based summary may be more appropriate and achievable using steps one and two of Thomas and Harden’s thematic synthesis.21 Extracted data will be combined and described using the most appropriate method to reflect the evidence available. Where possible, an interpretative account of the data will be presented in the context of a critical review of the evidence. The descriptive or conceptual outputs will be related to the research questions and objectives.

DISCUSSION

Insights from the proposed review will contribute to what is known, giving novel attention to the combination of cancer with other long-term chronic conditions. This is considered a necessary step in cancer survivorship research and care in the face of the increasing, ageing population and the shifting emphasis in patient care.

Building on the knowledge base will contribute to an evidence-based and conceptually informed integrated model of care, with an emphasis on better understanding experiences of complex and multiple conditions and the implications for living with cancer and comorbid illness in the push towards shared care or self-management.39

While conceptual and theoretical insights to a subject area can add richness to the academic evidence base, it is important to produce a robust qualitative synthesis that reflects the identified evidence.44 A narrative summary can adequately meet the proposed objectives, provide answers to the research questions and speak meaningfully to policy directives.

The findings from the review will combine with patient engagement work by the authors to inform an empirical study exploring the needs of the defined patient group and the development of an intervention to better address their complex needs. The review will be published in a peer-reviewed journal and presented at relevant conferences in addition to being shared with local interest groups and via online social media.

Acknowledgements We thank Ms Marshall Dozier, Academic Liaison Librarian, for advice on designing the review and searching literature databases and Dr Karen Barnett for advice on defining included long-term conditions.

Contributors DC designed the systematic review with input from CC, SC-B, EW and EB. DC drafted the review protocol with input from CC, SC-B, EW and EB.

Funding This review has been funded by the Scottish Government’s Chief Scientist Office (CSO); funding reference number: PDF/15/06. The CSO have provided copyright clearance for advice on designing the review and searching literature databases and Dr Karen Barnett for advice on defining included long-term conditions.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

Open Access This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/

REFERENCES

Experience of living with cancer and comorbid illness: protocol for a qualitative systematic review

Debbie Cavers, Sarah Cunningham-Burley, Eila Watson, Elspeth Banks and Christine Campbell

BMJ Open 2017 7:
doi: 10.1136/bmjopen-2016-013383

Updated information and services can be found at:
http://bmjopen.bmj.com/content/7/5/e013383

These include:
References
This article cites 29 articles, 7 of which you can access for free at:
http://bmjopen.bmj.com/content/7/5/e013383#BIBL

Open Access
This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/

Email alerting service
Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Topic Collections
Articles on similar topics can be found in the following collections
Oncology (396)

Notes

To request permissions go to:
http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to:
http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to:
http://group.bmj.com/subscribe/